EAST KENT HOSPITALS UNIVERSITY NHS FOUNDATION TRUST

REPORT TO:	**BOARD OF DIRECTORS – 29 AUGUST 2014**
SUBJECT:	**PATIENT STORY**
REPORT FROM:	**CHIEF NURSE AND DIRECTOR OF QUALITY & OPERATIONS**
PURPOSE:	**FOR INFORMATION AND DISCUSSION**

CONTEXT/REVIEW HISTORY/STAKHOLDER ENGAGEMENT
The Board of Directors have been using patient stories to understand from the perspective of a patient and/or a carer about the experiences of using our services.

Patient stories are a key feature of our ambition to revolutionise patient and customer experience. Capturing and triangulating intelligence pertaining to patient and carer experience from a variety of different sources will enable us to better understand the experiences of those who use our services.

Patient stories provide a focus on how, through listening and learning from the patient voice, we can continually improve the quality of services and transform patient and carer experience.

SUMMARY:

This month's story relates to the experiences of a person with a long term condition that flares up from time to time requiring frequent admission and day attendance to the hospital. It is a pertinent story because it describes the difficulties this patient had as someone who is an expert in dealing with their condition whilst being cared for and having treatment decisions made by the medical experts. It outlines the importance of listening to patients who have competence in their own care and knowledge of their own condition.

IMPACT ON TRUST'S STRATEGIC OBJECTIVES:

Improving patient experience and satisfaction with the outcomes of care are essential elements of our strategic objectives.

FINANCIAL IMPLICATIONS:
None

LEGAL IMPLICATIONS / IMPACT ON THE PUBLIC SECTOR EQUALITY DUTY:
None

PROFESSIONAL ADVICE TAKEN ON ANY NOVEL OR CONTENTIOUS ISSUES:
None

BOARD ACTION REQUIRED:

(a) to note the report
(b) to discuss and determine actions as appropriate

CONSEQUENCES OF NOT TAKING ACTION:

If we do not learn from events such as these there is an increased risk of further occurrences which may adversely affect both patient experience and outcomes.

Board of Directors
Patient Experience Story
August 2014

Introduction and Background

This month's story relates to the experiences of a person with a long term condition that flares up from time to time requiring frequent admission and day attendance to the hospital. It is a pertinent story because it describes the difficulties this patient felt they had as someone who is an expert in dealing with their condition whilst being cared for and having treatment decisions made by the medical experts. It outlines the importance of listening to patients living with a long term condition.

This is the story of a 27 year old lady (CF) who lives with the long term condition Systemic Lupus Erythematosis (SLE). This is a condition where the immune system attacks the body's cells and tissues. This results in inflammation and tissue damage. SLE most often harms the heart, joints, skin, lungs, blood vessels and nervous system. The course of the disease is unpredictable, with periods of illness (called *flares*) alternating with remissions. This is a condition that CF has lived with for many years. She is well known to the teams caring for her as they have been seeing her regularly over the past eight or nine years. CF attends Marlowe Ward on a weekly basis and views this ward as her regular ward and is where she is admitted should she become unwell. CF has become very well versed with SLE; she knows and understands the condition, and she is particularly attuned to her body and when changes occur, or if she becomes unwell. For her it is of paramount importance that she is listened to by the nursing and medical teams for her to have confidence in us and also for us to appreciate when she needs help associated with SLE flares, or other illnesses that may develop.

The Patient Story

CF was admitted to Marlowe ward on July 15th 2013. On the 10th July she had attended as a day patient for her regular infusion. Unfortunately this infusion was administered at 3 times the speed than was safe for her. This resulted in CF having a headache and neck ache. This mistake in itself did not overly worry CF as she resolved the issue at the time with the Ward Manager. Afterwards she began to feel unwell over several days. She felt confused in her surroundings and was struggling to carry out simple tasks. She was suffering swinging fevers, nausea and the head and neck aches continued. Her fear was that she was developing SLE in her brain. She contacted her Consultant who said to attend Marlowe Ward. Here she was attended to by several of the medical team.

It was during this phase of her care that CF felt as if she wasn't being listened to and did not have confidence in the team looking after her; she felt that they did not know her or fully understand her condition and how it affects her personally. Examples of this were that she does not normally show in her blood tests the normal raised levels that depict the presence of an infection. This is due to her immune system being affected by her condition. Her blood tests on this occasion did reveal an abnormality that meant she felt she required urgent attention. She was now developing neck stiffness as well and her arms were feeling numb.

Another example where this lady did not feel we listened to her about her condition was when the staff were taking her temperature. She has very small ear canals so the normal thermometers used on the ward do not fit in her ear well enough to gather an accurate temperature. She knew she had a raised temperature, but the nurses were taking readings that were recorded as normal. CF tried to explain this and indeed had her own thermometer. She said she went to great pains to explain this important information to all those looking after her.

A number of doctors attended to this lady during the course of her stay, and she continued to try to explain how unwell she was feeling. By now she was into week 2 of her stay and her kidney function seemed to be deteriorating. The team commenced fluids for her, but still she felt feverish. By this time she could barely move her head, was photophobic and was worrying that she had meningitis. She was reviewed by a Registrar and voiced her concerns, but according to CF she was told that she did not have meningitis, although she said she was not examined for this. A second Registrar examined her and did find signs of meningitis. She was feeling desperate and not believed and as though her current medical condition was being trivialised. On the 25th July she was discharged home, but on July 26th woke up feeling much more unwell. She presented at St Thomas' Hospital where she was taken straight to the Resuscitation area and was found to be seriously ill.

Summary

This story describes the distress of a patient who felt that they were not being listened to by those caring from them. The story is told from the letter of complaint that the patient sent to the Trust. As part of the investigation of the complaint a difference in accounts between the patient and the medical teams emerged. The medical teams stated in their responses that CF's condition was improving over the period she was with us. Her observations and tests were stable, despite the temperature recordings, and they gave sound clinical rationale for their clinical decision-making that was guided by best practice, patient safety and in the best interests of the patient. Apologies have been given to CF regarding the abruptness of one of the Doctors and this has been also given in writing along with explanations of the clinical decision-making that took place. In order to resolve the concerns of CF, a meeting was arranged with the Divisional Medical Director and member of the Patient Experience Team. A number of actions and outcomes were identified from the meeting along with an apology for her distressing experience.

Learning and Actions

The key actions that have been identified and taken are:

1. A need for clear plans for building confidence and trust in opinions of the medical team caring for CF in the future. The action taken was to seek some written guidance from the Royal Free team with regard to managing flares of SLE and episodes of infection in a patient with SLE;

2. An apology was made regarding the communication by the Doctor at KCH and also the breakdown in the relationship that occurred. Her routine care was transferred to a Consultant at Margate;

3. If CF requires immediate emergency care she will attend KCH and an early transfer to Guy's & St Thomas' Hospitals or the Royal Free Hospital will be arranged. This was to ensure a safe local port of call in an emergency to prevent travelling and also delays to the administration of immediate treatment that may be necessary;

4. More generally it was agreed that flexibility around assessments for patients should be highlighted. These were raised with the nursing staff and senior management. The Divisional Medical Director agreed to discuss with the staff on Marlowe ward the need to assess a patient immediately. Appropriate standards of care around this are essential and the Division agreed to audit these;

5. Training for the junior Doctors on the recognition of a sick patient, regardless of the recorded vital sign observations was agreed. The appropriate educational supervisors were informed;

6. Importantly, the staff were reminded of the importance of listening to patients who have competence in their own care and knowledge of their condition and why this is helpful rather than challenging.

These action points and learning were developed with CF as part of the meeting that was held. This patient has given consent for this story to be told and is still receiving her treatment as required.